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ABSTRACT

This issue paper is based on recommendations of a February, 1991 meeting on promoting child health through Part H of the Individuals with Disabilities Education Act (IDEA). Part H emphasizes family-centered care; service coordination; comprehensive services; collaboration among service providers and funding sources; outreach to traditionally underserved groups; and systematic, appropriate training. The first section of this issue paper, "A Welcome for Every Child," presents agreed upon basic principles and guidelines to support the health and development of infants and toddlers. The second section, "Lessons from Infants, Toddlers, and Their Families," uses four case vignettes to explore ways of providing both common and individualistic health and developmental needs. The third section, "Roles and Responsibilities," examines roles of families, health care providers, and other early intervention professionals. The final section, "Policies to Support People," suggests strategies that professional associations and educational institutions, as well as legislative and administrative bodies, can use to support health promotion through Part H. Appended are a list of 75 references and a list of the meeting participants. (DB)

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Promoting Health Through Part H

Promoting the Health of Infants and Toddlers with Disabilities through Part H of the Individuals with Disabilities Education Act

The Health Focus Group of the National Early Childhood Technical Assistance System (NEC*TAS)

Prepared by: EMILY FENICHEL

National Center for Clinical Infant Programs

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Preface

Part H of the Individuals with Disabilities Education Act (the IDEA) is a significant part of a growing national effort to improve health and developmental outcomes for vulnerable infants and toddlers. Part H emphasizes family-centered care; service coordination; comprehensive services; collaboration among service providers and funding sources; outreach to traditionally underserved groups; and systematic, appropriate training. Recently enacted maternal and child health, mental health, Medicaid, and child care legislation at the federal level share these emphases, as do many recent state and local legislative and administrative initiatives.

Promoting Health through Part H examines the challenges that Part H offers to practitioners, administrators and families to change, quite radically, their traditional ways of working to support the health and development of very young children with, or at risk for, disabilities. Using extended case vignettes to illustrate the complex issues involved in providing appropriate care to infants, toddlers and their families, this issue paper goes on to explore specific areas of responsibility—direct care, coordination of care, informing and counseling, and community advocacy.

Based on a two-day meeting convened by the Health Focus Group of the National Early Childhood Technical Assistance System (NEC*TAS), *Promoting Health through Part H* includes a number of specific recommendations for Part H lead agencies and Interagency Coordinating Councils, communities, associations, training institutions, and governmental bodies. Because many important issues concerning systems of care for infants, toddlers and their families remain unresolved, the most important recommendation for all who care about this population must be: Engage in the dialogue; take an active role in policy development.

It is hoped that this issue paper will be useful to individuals and organizations that represent a wide range of perspectives on the complex questions discussed. An effort has been made to avoid the terminology of any single discipline and to convey something of the flavor of the Health Focus Meeting itself. Readers are encouraged to consult the resources cited at the end of the paper and the participants themselves.

Introduction

Adam is a two-year-old boy who is assisted with a ventilator. His resilience continues to impress his parents and the many health professionals who have cared for him since his premature birth. Eva is a charming six-month-old with Down syndrome. George, 15 months, has always seemed a fussy, difficult child; now he is failing to gain weight. Hope, 12 days old, has not yet left the hospital.

In the first three years of their lives, Adam, Eva, George and Hope will need immunizations. They will need car seats. They will need treatment for ear infections and colds. They will throw tantrums. They will have nightmares. They will need to learn how to make friends.

It is possible to imagine Adam, Eva, George, and Hope as patients in a community family medicine or pediatric practice, and as participants in a community early intervention program. It is possible to imagine their parents, health care providers, early intervention professionals, and other caregivers consulting regularly and comfortably with each other about both the ordinary and the atypical challenges involved in fostering the health and development of these children. But given the complexity of these children's lives, the diverse circumstances of their families, and the persistent fragmentation of services for young children, it is also possible to imagine that Adam, Eva, George, and Hope will not get the comprehensive health and developmental support they and their families need in the first three years of life.

Part H, enacted in October, 1986, as P.L. 99-457, the Education of the Handicapped Act Amendments and reauthorized as part of IDEA (P.L. 101-476), can be seen as a significant part of a growing national effort to improve health and developmental outcomes for Adam, Eva, George, Hope, and other vulnerable infants and toddlers and their families. Part H emphasizes family-centered care; service coordination; comprehensive services; collaboration among service providers and funding sources within the community and at the state level; outreach to traditionally underserved groups; and systematic, appropriate training. Recently enacted maternal

and child health, mental health, Medicaid, and child care legislation at the federal level share these emphases, as do many recent state and local legislative and administrative initiatives.

Part H challenges practitioners, administrators and families to change, quite radically, their traditional ways of working to support the health and development of very young children with, or at risk of, disabilities. The challenge is directed to everyone involved. The infant and toddler portion of the law does not mandate the adoption of any one existing model of practice or service delivery, but rather provides incentives to create a new, integrated system of care, one that reflects advancing knowledge of development in the first three years of life and that enlists all available skills and resources to support infants, toddlers and their families.

Unfortunately, the challenge of Part H comes at a time when human and financial resources are severely, and almost universally, strained. Even with two wage earners, families are strapped financially; work and family demands are, at best, in a precarious state of balance. Physicians and other health care providers are torn between their professional obligation to prescribe the care required by each individual patient and the limitations placed on their services and resources by third-party payers, or by other limitations in public and private, nonprofit funding. In agencies and legislatures, competition for human services appropriations threatens to pit advocates for children against advocates for the elderly, the needs of children with disabilities against the needs of children at risk. Such a climate is likely to encourage defensive circling of the wagons, rather than bold exploration of new frontiers.

Nevertheless, since the enactment of Part H in October, 1986, parents, policymakers, administrators and front-line professionals in all parts of the country have been taking advantage of the opportunities for policy development and implementation afforded by the law. They have been evolving a shared vision of integrated services to promote the health and development of infants and toddlers with disabilities. They have identified barriers to realizing this vision. They are devising strategies to support each other in new roles. The formation of the Health Focus Group of NEC*TAS, the National Early Childhood Technical Assistance System, was itself a response to the requests of Part H administrators, state Interagency Coordinating Council chairs, the NEC*TAS Advisory Board, and others for more attention to promoting health within the context of Part H.

On February 25-27, 1991, the Health Focus Group brought together 23 individuals from all parts of the country, repre-

senting a range of administrative and practice responsibilities, training, and personal experience (see Appendix B for a list of participants). As this group worked to delineate a common agenda, identify sources of misunderstanding, understand complex institutional and personal relationships, and suggest practical strategies for "getting on with the job," we began to find abstractions dominating our discussion—"systems of communication," "interagency collaboration," "service coordination." What did this all **mean**?

At this point in the February meeting, Adam, Eva, George, and Hope were conceived. We imagined four very young children and their families. We thought about what their health and developmental concerns, priorities and resources might be. We considered the specific services and the systems of care that might be available to Adam, Eva, George and Hope, and the ways in which connections might be made, or missed, between and among these children, their families, and sources of support. By thinking early in our discussions about service delivery issues as they affect individual children and families, we were able to use these concrete conceptualizations to make some generalized recommendations in later discussions. We found it helpful to think of policies not as abstract statements but rather as incentives for individuals to behave in specific ways.

Thinking about service delivery issues as they affect individual children and families is a useful prelude to making generalized recommendations.

Occurring as it did in February, 1991, the dialogue in the Health Focus Meeting built not only on the decades of research and clinical expertise that preceded the passage of P.L. 99-457 but also on more than four years of experience in planning for and implementing Part H services as described in the legislation.

Meeting participants agreed easily on basic principles and guidelines that underlie all our work to support the health and development of infants, toddlers and their families in the earliest years of life. These are discussed in the first section of this paper, *A Welcome for Every Child.*

The second section, *Lessons from Infants, Toddlers and Their Families,* uses the case vignettes of Adam, Eva, George, and Hope to explore ways of approaching the health and developmental care of very young children with disabilities—the needs they share with all infants and toddlers as well as those specific to their individual or family circumstances.

The third section, *Roles and Responsibilities,* examines the variety of roles that families, health care providers and other early intervention professionals may assume in order to promote the health of infants and toddlers with disabilities.

The final section, *Policies to Support People,* suggests strategies that professional associations and educational institutions, as well as legislative and administrative bodies at every level of government, can use to support the promotion of health through Part H.

Appendix A contains a list of selected references related to the promotion of health in Part H and to the role of the various health and allied health disciplines in Part H. A list of NEC*TAS publications is followed by a reference list organized in two sections. The first section includes journal and newsletter articles; the second section includes books, monographs, and reports.

Appendix B lists participants in the February meeting and identifies members of the NEC*TAS Health Focus Work Group.

Section One: A Welcome for Every Child

During the first three years of life, health and development are inextricably linked, perhaps more so than at any other period in the human lifespan. Infants, even newborns, possess powerful drives toward mastery, but these are combined with physical and emotional vulnerability. Each infant's blend of strengths, sensitivities and vulnerabilities is unique.

The caregiving environment is central in mediating the child's experience. The quality of the caregiving environment protects, or jeopardizes, the infant's basic physical survival; the quality of the caregiving environment also determines the extent to which the baby's individual health and developmental needs will be met.

Development unfolds rapidly during a child's first three years. Consequently:

- **Risks are graver in the earliest years of life.** For example, inadequate nutrition in the first months and years of life may result in irreversible damage, whereas similar deprivation in later years may be less devastating.
- **Timing is critical.** For example, a medical procedure that temporarily restricts mobility will mean different things to a toddler than to a newborn. So will separation from familiar people and surroundings, or physical pain.

Parents and professional child development experts would agree that in order to understand and promote the health and development of children from birth to three, and seek a balance between concurrent medical, health and developmental priorities, one must attend to:

- the relationship between physical and emotional health and well-being;
- the interaction among multiple lines of development—motor, cognitive, communicative, social, and emotional; and
- the complex, evolving relationships among the child, family, and community.

Whether they are coping with the "ordinary" stresses of balancing work and family obligations, or facing the special

challenges of an infant with a disability, adaptation to a new culture, economic hardship, and/or difficult family relationships, all parents of infants and toddlers deserve support. The French call their child care system "a welcome for every child." The phrase captures well both the overall philosophy of Part H of the Individuals with Disabilities Education Act (IDEA) and the specific goal of attending to the linkage of health and development within the context of Part H of the act.

The family of every child should feel welcome at a health care source that offers both preventive health care and treatment of health problems. A "welcome" implies many things parents look for in a health care source—safety, comfort, knowledge, and nurturance. A welcome also suggests physical accessibility, cultural appropriateness, and freedom from financial barriers.

A welcome for every child suggests availability without officiousness, and attentiveness to individual needs without intrusion. The welcoming primary health care source offers continuity of care, the opportunity for a child and family to be truly "known" over time. This offer translates to maintenance of records, linkage to the whole range of health care services, and anticipatory guidance appropriate to each child's unique health and developmental course.

Accessibility, affordability, continuity, respect, developmental appropriateness, and flexibility are, of course, features critical to the effectiveness of any program or system designed to support families in their childrearing. They should be part of the "welcome" afforded families in the child care center and in the well baby clinic, in the neighborhood family resource program and in the early intervention setting, in the NICU and the public library, the WIC office and the corporate personnel office.

In considering the importance of offering a welcome to infants, toddlers and their families, one must also remember that "first" relationships powerfully determine future expectations—for children, for parents, and for professionals. For better or worse, expectations based on early experiences are difficult to change. Thus, health care and other early intervention professionals need to pay explicit attention to the quality of the relationships they establish with infants, families and each other. They need to remember that:

- Parents are the continuing, central shapers and mediators of their infants' experience. However, confidence in taking control and in decisionmaking may take time to emerge in first-time parents, or in experienced parents who have an

infant with special needs. Health care and other early intervention professionals have a unique opportunity to confirm and support parents as they assume new decisionmaking roles.

- In their interactions with families and professional colleagues, health care and other early intervention professionals can affirm and honor the family's culture, race, language and ethnicity, their traditional or unique composition, their values, and their choices.
- First-time parents and parents of infants and toddlers with disabilities are engaged in developing specific expertise. They acquire skills in breastfeeding and gavage feeding; in assessing the level of their children's distress from the pitch of a cry or the signal of a monitor; in reading behavioral cues; in evaluating the quality of services; and in advocating on behalf of their children. Health care and other early intervention professionals can assist parents in acquiring specific new skills and can, in turn, listen to and learn from the experience of parents.
- As they coordinate their interactions with parents and with each other, health care and other early intervention professionals can provide models of sensitivity, respect, and candor.

By making explicit and sustained efforts to establish mutually respectful and satisfying relationships as they work together to support the development of infants and toddlers, professionals and parents may affect systems of change for individuals with disabilities of all ages. They will have "grown up" together in family-centered care, and will expect it to continue.

However, the stories of Adam, Eva, George, and Hope remind us of the complexity of the challenge.

Section Two: Lessons from Infants, Toddlers and Their Families

The exercise of imagining Adam, Eva, George, and Hope and their families served to remind participants in the Health Focus Meeting of the intricate links between health and development in the first three years of life. Group discussion made vivid the complex challenges and decisions families face, as well as the importance of natural supports. Discussion illuminated the gaps between the services that are available today for many infants and toddlers and a system of care—achieved, in part, by promotion of health through Part H—that would truly "welcome" every child and family.

Although they are elaborated in some detail, the vignettes of Adam, Eva, George, and Hope and their families can only begin to suggest the complexities of any actual family's circumstances. Individually and as a group, however, the vignettes provide a basis for discussion among people with different perspectives:

- Readers familiar with the paradigm of "family-centered, community-based, comprehensive, coordinated" care for children with special health care needs may see Adam's story as highlighting the issue of community-based care, Eva's story as emphasizing family-centeredness, George's story as addressing coordination, and Hope's story as stressing access to comprehensive services.
- Readers who are involved in the planning and implementation of Part H services may see the vignettes as a way to stimulate thinking about specific aspects of the law and the system as a whole. For example, how might each child and family in the vignettes become connected to Part H services once they are in place? How would IFSPs look for each of these children and families? What are the issues in care coordination raised by each vignette?

Each vignette is followed by an exploration of one or more issues that emerged in the Health Focus Meeting discussion of that child and family. Sections III and IV of this document, *Roles and Responsibilities* and *Policies to Support People,* contain more general formulations and recommendations.

Adam

Adam is a two-year-old boy, assisted with a ventilator, who commutes regularly from his small town to a regional medical center three hours away. This happens monthly when Adam's health is stable, more frequently when he has a respiratory infection.

Adam was born in the regional medical center, at 25 weeks gestation. His mother, Lily, had been hospitalized there for three weeks in what proved to be an unsuccessful attempt to maintain the pregnancy. In the Neonatal Intensive Care Unit, Adam fought for survival, emerging with bronchopulmonary dysplasia (BPD) and a Grade Two intracranial bleed, which places him at risk for cerebral palsy. When Adam first went home, at eight months of age, he was dependent on the ventilator. Now he can be off the ventilator almost all day, and his medical condition is stable more often than not.

In some ways, staff at the medical center are like extended family to Adam and his parents. Last Christmas, Lily sent 14 cards to staff members at the medical center (and 5 to people who had once worked with Adam but had changed jobs). A core team of a pediatrician, two nurses, a nutritionist, a social worker, an early childhood special educator, an occupational therapist and a respiratory therapist has been monitoring Adam's health and development regularly and consulting with his parents. There are snapshots of Adam on the bulletin boards of the Neonatal Intensive Care Unit, the Pediatric Intensive Care Unit, and the High Priority Follow-up Clinic. Lily and Adam "co-taught" a grand rounds session for pediatric residents and graduate nursing students.

Caleb, Adam's father, is a skilled machinist. His union-negotiated health insurance paid for Lily's costly prenatal care and has covered Adam's medical care so far, but the $750,000 insurance cap, which once seemed as unreal to Caleb as the Pentagon budget, is now a source of persistent anxiety. There are no opportunities for advancement at Caleb's plant; indeed, rumors of layoffs circulate with some regularity. With eight years of seniority, Caleb feels safe, but stuck.

Lily feels as if she has spent the two years since her pregnancy with too much to worry about and not enough sleep. Sometimes she tells her favorite nurse at the medical center that the three weeks in bed before Adam's birth were the last time she got enough rest.

Lily has become expert in monitoring and meeting Adam's complex physiological needs. She feels she and Caleb have

brought Adam this far by "taking one day at a time." She appreciates Caleb's positive outlook and steady determination to provide, but herself makes a point of not planning too far ahead. As Adam's health has stabilized, however, Lily has started to experience more vividly the burden of the daily routine of care and the long trips to the medical center. She would like to go back to work and start saving for the down payment on a house.

Meeting Adam's health and developmental needs—a community responsibility?

As they began to discuss Adam's health and developmental needs, Health Focus Meeting participants discovered the needs of Adam's family and community as well. Not many years ago, Adam would have been considered a "miracle baby," his survival and discharge home a singular triumph of medical science and technology. Now the challenge is to provide coordinated care **in the community** for children, like Adam, with special health care needs. What is involved?

Like all two-year-olds, Adam needs medical care for prevention, monitoring, and treatment of acute illness. Adam also requires periodic comprehensive assessment of his health and development, including an accurate medical diagnosis upon which to construct an appropriate plan of services. For Adam, competent medical care is literally a matter of life or death, but medical care will not meet all of his needs.

Adam needs both ordinary **experiences,** like contact with other young children, and extraordinary **things,** like special equipment and supplies. Adam can benefit from specific caregiving strategies to protect him from exposure to disease and to encourage his motor development (including feeding skills), physical growth, emotional development and communication skills. The challenge is to make services of knowledgeable personnel available to Adam and his family in the context of ordinary community life.

Now that Adam is two and relatively stable medically, his family is beginning to think about the "big picture"—Adam's future and their own. The process of determining family concerns, priorities and resources is not a simple one. Who will assist Caleb and Lily in determining their needs? Ironically, Adam's family has until now achieved "one-stop shopping" coordination of services through the regional medical center. A service coordinator who undertakes to work with the family to meet its complex needs within the community is likely to have a hard act to follow.

In order to provide integrated medical, health, and developmental services that are physically and psychologically close to home, the community must acknowledge responsibility either to provide services or to ensure their provision.

Looking at Adam and his family at a potential turning point in their development sharpens our focus on community needs. In order to provide integrated medical, health and developmental services for Adam that are physically and psychologically close to home, the community must acknowledge responsibility either to provide services or to ensure their provision. Community "ownership" of such responsibility reflects community values. Community planners and providers must be willing to commit energy and resources to make "caring for one's own" a reality for Adam and his family. (In many ways it is easier to let Adam "belong" to the regional tertiary level medical center.)

A local planning group, such as a local Interagency Coordinating Council, can be critical in a community's own development. Thinking about Adam, Caleb, and Lily, a local planning group might initially address:

- the identification of a local physician willing to assume responsibility for Adam's ongoing or routine medical care, or the training of the family's chosen provider to handle Adam's needs;
- the capacity of local emergency medical services to plan for Adam's needs;
- preparation of local early intervention services to understand and accommodate Adam's health care requirements as well as developmental needs;
- local resources, like the library or Y, where Adam can go to play, learn, and develop relationships with his nondisabled peers; and
- potential sources of respite care.

The process of identifying and coordinating such services in the community is likely to illustrate for all involved the importance of ensuring that those resources that do exist in the community are genuinely accessible to the family. Moreover, such a process is likely to heighten awareness of the need for a community system of care for all children, within which children with disabilities and their families can thrive.

An historical perspective: Sources of power and responsibility

Part H of P.L. 99-457 became law at a time when states and governing jurisdictions were seen as the appropriate places in which to develop and implement comprehensive service delivery systems for infants and toddlers with disabilities. Part H lead agencies and Interagency Coordinating Councils in the states are struggling with the complexities of achieving coordi-

nation among state-level agencies with varying traditional mandates and funding levels, while simultaneously adhering to federal regulations and being responsive to local needs.

The circumstances of Adam and his family are a reminder that federal, state and local government are by no means the only sources of funding or policy where health and developmental issues are concerned. For example, it is Caleb's health insurance that has so far paid for Adam's medical care. What is available to Adam through that insurance reflects negotiation among his father's union, his employer, and a large private insurer. The regional medical center that has been so important to Adam and his family is precisely that—a **regional** medical center, designed to serve a geographic area that includes parts of three states. The center draws on the expertise of a health sciences university, which is under the auspices of a religious order. All of these sources of expertise and authority—unions and religious orders, universities and insurers, corporations and governmental agencies—represent evolving attempts to address changing human needs.

The circumstances of Adam and his family serve to highlight changing expectations of individuals, as well as of institutions. Forty years ago, Adam's grandfather and grandmother had distinct, although complementary, roles as breadwinner and homemaker. Adam's parents recognize that in order to have the house that means "home" to them, they may both have to be wage-earners. They are searching for a comfortable balance among work, family and individual demands, and for a family life connected to the community. They are trying to remain true to enduring values, even as they renegotiate specific roles.

Changing expectations of professionals likewise need to be seen in the context of preserving important values. Professionals have a dual responsibility for personal competency, as defined by the standards of their profession and by public authority, and for respect for the competencies of fellow professionals and families. As professional roles and responsibilities evolve in response to new scientific knowledge, accumulating clinical experience, and changes in social policy, care must be taken to assure that both professionals and families who assume new roles are well trained for the tasks they undertake.

Eva

Eva is a charming, healthy six-month-old girl with Down syndrome. Her sister Laura is 18 months old. Eva's mother, Isabel, who is 19, came here from El Salvador after her husband was murdered; she was pregnant with Eva at the time.

Isabel sees herself as a fighter. A refugee organization directed her to prenatal care offered by volunteer physicians, nurses and students to women ineligible for Medicaid benefits. When Isabel's labor began, she was taken by taxi to the emergency room of the public hospital, which was required to accept her. Fortunately, labor and delivery went smoothly.

Eva's Down syndrome was identified immediately after birth by the delivery room physician and nurses. The pediatric resident was called in later the same day to discuss the baby's condition with Isabel. With him was the hospital's social worker, who is Latino. Although the resident was sensitive to the mother's possible feelings, she did not know a great deal about the ongoing developmental needs of children with Down syndrome or resources for their families. The social worker, however, was aware of the community support group, Parents of Children with Down Syndrome, and asked Isabel if she would like a Spanish-speaking parent to visit her. Through this connection, Isabel and Eva became involved with a bilingual early intervention program very soon after Eva's birth.

Isabel now has a Medicaid card for Eva, but has not yet established a connection with either a public health clinic or a private provider as a continuing source of primary health care. At six months, Eva seems healthy. Her sister and cousins are generally robust as well; there have been one or two family visits to the emergency room of the public hospital for treatment of respiratory infections since Eva's birth, but no complications.

Isabel's English is not yet proficient. Isabel, Laura, and Eva live with Isabel's brother, Miguel, his wife, Rosa, and their three children in a two-bedroom apartment. The neighborhood has a high incidence of lead poisoning. Isabel works three days a week as a housekeeper in a downtown hotel. Rosa cares for all the children during the day, thus relieving Isabel of child care expenses. But since she works several nights a week as a nurse's aide, there are occasions when her eight-year-old daughter is asked to supervise the four younger children while Rosa naps.

Creating a "welcome"

We are told that a pediatric resident and a Latino social worker visited Isabel while she was still in the hospital after delivery, to discuss the baby's condition. Participants in the Health Focus Meeting discussed how such a visit might go.

It was suggested that health professionals should assume that families expect to be able to find primary health care for their infants in the community. A hospital staff member can ask parents of newborns what thoughts they have about the source of such care and what they expect providers to do. If a newborn is known to have special needs or is considered at risk for a medical, health or developmental problem, the professional can explore with the family the extra resources that may be useful to them and the primary health care provider. Other participants noted, however, that some families perceive, correctly or incorrectly, that local resources are unlikely to meet the needs of their child or family. They may expect to use resources outside the community or feel that they must make do without assistance from "the system."

In approaching families, it is important for professionals:

- to know the family's expectations;
- to know their own professional limits;
- to know, and be able to explain, options; and
- to know how to make a referral that will "take"—that is, a referral that will seem appropriate to the family and provider and that will facilitate connection.

We are not told what meanings Eva's birth or the diagnosis of Down syndrome had for her mother. It will be important for those working with the family to listen carefully, as these meanings may be revealed over time. We do know that thanks to some combination of Isabel's own style of coping, her family's support, her experience with professionals in the hospital, and her experiences with parents and early intervention program staff, a "welcome" has been created for Eva. It is important to recall that, while still a teenager, Isabel has demonstrated resourcefulness far beyond that required of most adults during an entire lifetime. She has trusted herself and has been able to place trust in others, during the perilous journey from her homeland and in her new community.

As they imagined the life circumstances of Eva and her family, participants in the Health Focus Meeting spoke of feeling overwhelmed by the thought of so many urgent needs—for more income, better housing, adequate food, child care, medical care, and educational opportunities, among others. That these feelings could be so strong in a group of seasoned practi-

tioners as they considered a hypothetical family is instructive—what is likely to be the experience of the individual early interventionist who works with such families in the "real world?"

This discussion reinforced participants' appreciation of the benefits of the Individualized Family Service Plan in Part H for practitioners as well as families. As the expression of a family-centered approach to service, the IFSP provides Isabel the opportunity, working in partnership with early intervention professionals, to identify her own concerns, resources, and priorities. As these change, so will the plan. The accomplishment of short-term goals is likely to encourage both family and professionals to take on larger challenges.

Strengthening community resources

According to the vignette, Eva seems healthy at six months—but she is not receiving preventive care and supervision from a continuing source of medical care. Eva needs the monitoring and immunizations important to any infant her age, and since she has Down syndrome, her regular check-ups should also include cardiac evaluation and monitoring of hearing, vision and thyroid function, as well as growth monitoring and anticipatory guidance to prevent obesity and assure an adequate diet. Anticipatory guidance needs to be provided by a health care professional who is knowledgeable about Down syndrome, willing to share observations with early intervention program staff, and able to communicate fully with Isabel in her own language.

It is possible to feel overwhelmed by the thought of many urgent needs. The IFSP enables parents and professionals to identify concerns, priorities and resources together.

These needs suggest areas in which existing community resources are likely to require strengthening if Eva and her family are to be well-served:

- A tracking system designed to link at-risk newborns with sources of primary health care in the community would register a failure to connect well before a child reaches six months of age, and follow-up procedures would help the family find care.
- Community health and other early intervention professionals, including nutritionists, public health nurses, physicians and social workers, need to be aware of the appropriate protocols for monitoring and treating young children with Down syndrome. Information may be disseminated by state and local health departments and/or professional associations.
- General awareness about the specialized well child care required by infants and toddlers with disabilities or special

health care needs should be reinforced as each individual child is served. For example, the representative from Parents of Children with Down Syndrome might give Isabel information to share with Eva's physician. Hospital referrals might include a reminder about the appropriate protocols for well child care of children with Down syndrome. The early intervention program might make a point of emphasizing to Isabel and other parents the importance of special well-child care.

Eva and her cousins seem healthy, but their living situation may place them all at serious risk for accidental injury and lead poisoning. Concern is growing, at every level of government, as well as among researchers, practitioners and the general public, about the devastating impact of these risks. Funds for injury prevention, screening and treatment for lead poisoning, and lead abatement programs are currently available from a number of sources, some of which, such as departments of environmental affairs or privately-funded safety awareness campaigns, may not be represented in Part H planning processes. One issue for all the professionals who may be involved with Eva and her family, and for parent groups as well, is how to build protection from environmental hazards into individual plans of care. Another issue is how to engage in the development of appropriate and effective public health policy.

George

George is 15 months old. He has always seemed a fussy, difficult child to Brooke and Oliver, his parents, but as first time parents they haven't been sure what the "norms" are. The maternal grandmother worries about George, especially when she hears about his feeding difficulties, but "Don't interfere" is her motto. At the child's last check-up, the physician's assistant noted that, according to standard growth charts, George is failing to thrive.

In truth, George has been failing to achieve other developmental milestones as well, particularly in the areas of social and emotional growth. He has been cared for by five in-home caregivers during the 15 months of his life; his longest relationship with a caregiver is the current one, and has lasted five months. Although Brooke and Oliver looked forward to spending "quality time" with their firstborn son, George's fussiness has not made their interactions rewarding. Brooke and

Oliver are well-educated, successful professionals. They do not yet feel successful as parents, but they have not been able to voice their concerns.

George, for his part, is not the kind of baby who can incorporate and thrive on whatever morsels of emotional nurturance may be scattered throughout his caregiving environment. His need for low-keyed, consistent caregiving, responsive to his unique cues, has gone largely unmet.

When problems are "nonspecific"

Participants in the Health Focus Meeting noted that "nonspecific" developmental problems represent a significant challenge to a comprehensive system of services for infants, toddlers and their families. Timing is key—for identification of concerns, meaningful assessment, and appropriate intervention.

Meeting participants observed that the term "at risk population" often conjures up an image of young children in a chaotic or deprived caregiving environment, including an unskilled adolescent mother and lacking in social or economic support. The circumstances of George and his family are a reminder that risks to healthy development and a strong parent-infant relationship exist at all levels of parental income and education. Family-centered care is for **all** families.

In some ways, it is fortunate for George that he has failed to gain weight at the rate expected for his age. In current American pediatric practice, this phenomenon will be noticed readily if an infant or toddler is receiving regular primary health care. In George's case a standard growth chart documented the discrepancy. "Failure to thrive" is a loud warning signal. Unfortunately, it is not always a clear one.

One can imagine a scenario in which there had been a better "fit" between the strengths and needs of George and his family and the resources available to them:

- Hungry and malnourished babies are irritable and lethargic. Suppose that George's in-home caregiver had been able to help him establish a more satisfactory pattern of feeding, and find ways to soothe himself. He might have been more easily engaged in play by his parents.
- Suppose that George's grandmother had taken him for well-baby check-ups and developed a trusting relationship with the pediatrician. She might have shared her observations about George's difficult feeding situation and developed a strategy with the pediatrician to raise the issue with George's parents without undermining their authority.

- Suppose a "work and family" discussion group had been available to Brooke and Oliver at their places of employment.

It is possible that any of these supports, or a combination of them, might have resulted in patterns of caregiving more helpful to George's individual developmental needs or that shared concerns might have led to appropriate assessment, with linkage to specialized services if indicated.

Some children with nonspecific developmental problems may "fall through the cracks" of a service system.

Unfortunately, other scenarios are all too easy to imagine. Because they may be deemed ineligible for publicly supported early intervention services with narrow definitions of eligibility, some children with nonspecific developmental problems may "fall through the cracks" of the service system. On the other hand, a child of an affluent family may not receive the services he needs if his parents choose a "private entrance" to the service system. George's parents may spend a good deal of time and money searching for a "diagnosis" at both primary and specialized levels of care. They may also "shop" for specific therapies. The reimbursement practices of private third-party payers may encourage the prescription of isolated services or even hospitalization. Meanwhile, a **meaningful** understanding of George and his family is likely to remain elusive.

Both parents and professionals who are concerned about a child with poorly understood developmental problems need to tolerate hypotheses in the absence of a specific diagnosis. Perplexed professionals need the opportunity to talk with each other and to say, "I don't know." Parents need the opportunity to provide clarifying information about their children's development and behavior that can help in formulating a diagnosis. An interactive process in which the family's own concerns and priorities are clearly identified is important to assure an appropriate plan for assessment and intervention.

Models of referral (medical) and service coordination and provision (early intervention)

As they thought about George and his family, participants in the Health Focus Meeting found it useful to examine the models of care coordination that have become traditional in medicine and in early intervention.

The referral process is key to the medical model. This model is designed to assure that diseases or impairments are promptly and correctly identified and understood, so that appropriate treatment can be promptly offered. A physician faced with a diagnostic or treatment challenge beyond the scope of his practice will refer a patient to a more specialized

setting. There will be communication between the referring physician and the consultant. The physician will develop priorities for further assessment and/or treatment and recommend these to the family.

The tradition of early intervention emphasizes working with a family to identify all that needs to be done to support development, with no priorities recommended in advance by professionals. Planning for assessment is likely to take into account accessibility to the family and timing as well as the expertise of the assessment team or facility.

In either model, care coordination is a central issue. The primary medical or health care provider who is involved with the family independent of a Part H referral may take responsibility for this function, or it may be assigned in the context of Part H services. In either instance, a medical practitioner needs to be involved with a child and family over the long run. Responsibilities should be discussed and negotiated. What is important is that the family and all professionals working with a child and family be clear about what each practitioner will do, and what others will do.

Two scenarios for George

One can imagine a scenario in which George's pediatrician responds to his own and the family's concern about the child's rate of growth by referring the family for further medical and early intervention assessment. If he asks simply to be "kept informed," he may not have contact with the family until the next well baby check-up. If the failure to thrive clinic in the tertiary level medical center does not communicate with the primary care physician or the early intervention program, the potential exists for duplication of assessments, conflicting recommendations, a diversion of care away from the community level, and increased family stress.

In an alternative scenario, George's physician would make referrals to the same sources, but he would **specify** the information he would like from both the medical and early intervention assessments. He would ask that information be brought back to him so that a treatment plan could be developed with the family and all the professionals involved. In the course of this planning process, roles will be negotiated. The pediatrician may continue care coordination, or a non-physician care coordinator may be chosen. Whether or not the primary care physician takes an active role in the treatment of George's specialized medical needs and developmental program, he will have built bridges to colleagues and to George's

family, and will have improved communication throughout the system of care.

Time and money are very real barriers to "scenario two." The demands of patient care make it extremely difficult for medical professionals (and other practitioners in private practice) to spend hours at a planning meeting or even to keep up with written reports. Some states reimburse physicians for attending case management or discharge planning meetings. In other instances, physicians send representatives, communicate extensively with parents before planning meetings, or talk with the service coordinator.

Hope

Hope, 12 days old, has not yet left the hospital. Her 32-year-old mother, Mona, is a clerical worker in a small company that offers no health insurance benefits or sick leave.

Mona's pregnancy was unplanned and caused a rupture in the relationship with Hope's father. Mona had no prenatal care. She knew about the existence of public health clinics but was afraid to take the time from her job that prenatal care appointments would involve. Although she tried to cut down on her smoking and consumption of "junk food" during pregnancy, her success was uneven.

Mona went to the emergency room of her community hospital when labor began. Because the newborn had a rash and was small for gestational age, Hope was transferred soon after her birth to the Neonatal Intensive Care Unit (NICU) of Mercy Memorial Charity General Hospital, the tertiary care facility across town. There the diagnosis of cytomegalic inclusion disease (CID) was made. As a result of this congenital infection, caused by cytomegalovirus, Hope has central nervous system damage, feeding problems, a profound hearing loss, and suspected visual impairment.

Mona returned to her job two weeks after her giving birth but has visited Hope in the hospital every evening. Hope is due to be discharged from the hospital next week; she has stayed there longer than might have been medically necessary because of staff concerns about the adequacy of follow-up care. Exhausted, and worried about the medical care and special daily routines Hope will need, Mona is thinking about leaving her job and applying for Aid to Families with Dependent Children (AFDC).

The chance for a first connection

In the United States, almost all babies are born in hospitals. Even though appropriate prenatal care is far from universally accessible, as Mona found to be the case, the period of hospitalization around childbirth does provide an opportunity to link child and family to an ongoing system of care.

This opportunity may be fleeting. Had Mona given birth to an apparently healthy newborn, she and Hope might have gone home within hours of delivery, never having had a candid conversation about the family's circumstances, and with no clear link to medical or social support in the community. Ironically, Hope's CID has given her a "ticket of admission" to a well-staffed medical center.

At Mercy Hospital, the connections among medical, emotional and social well-being of both child and family are well appreciated, by administrative as well as clinical staff. Everyone knows that if a child like Hope is discharged before adequate plans have been made for follow-up care, she is likely to return in a few months for a hospitalization that probably could have been avoided. And, absent an alternative plan, the costs of such a stay will be borne by the hospital.

Enter the financial counselor

We are not told whether a fluorescent sticker with the legend "no insurance" was affixed to Hope's medical chart at the time of her emergency transfer from the community hospital delivery room to Mercy's NICU. In any event, the Mercy Hospital administration was alerted promptly to Mona's circumstances, and a financial counselor arranged to see Mona during one of her early visits to Hope. The counselor discussed the family's eligibility for Medicaid; she also raised the possibility that Hope might be eligible for Supplemental Security Income (SSI) benefits, which would include monthly cash income and, in most states, eligibility for Medicaid. The financial counselor will continue to be involved with Mona during Hope's stay and will be part of the discharge planning team, re-evaluating Hope's likely eligibility for SSI as her diagnosis and prognosis evolve.

Mona finds it a great relief to talk with the financial counselor. Anxiety about her precarious financial situation consumed her from early in her pregnancy and has cast a pall over her beginning relationship with Hope. As she discusses her options with the financial counselor, Mona recognizes the gaps in public and private health coverage for what they are. Her sense of personal failure is diminished. She is able to

think more clearly about what Hope needs and how she can mobilize the resources to care for her daughter.

Emotional support should also be offered by trained hospital staff to mothers like Mona immediately after childbirth, if not earlier. Among other things, Mona may feel responsible for her daughter's infection. And while the strengths of natural support systems are often underestimated, some parents are truly alone. Professional support or sensitive outreach by experienced volunteers may be necessary to help some parents establish connections to trustworthy informal sources of support.

Transition planning

Participants in the Health Focus Meeting outlined a series of steps that would assure Hope an appropriate transition from hospital to home and community.

An appropriate transition from hospital to home and community is critical.

One set of tasks constitutes a **process of identification** of circumstances, needs and resources. In the course of such a process, a social worker or hospital discharge planner learns about the family's community and whether a local physician is involved with the family. The worker then identifies resources in the community that may be appropriate for the child and family—for example, the public health community nurse, sources of medical care, and parent-to-parent support. A tertiary care hospital is likely to serve many communities, whether they are towns and villages dispersed over a geographically large catchment area or the culturally distinct neighborhoods that may make up a large urban center. To do an effective job, the hospital worker needs a network of colleagues sufficient to identify as comprehensively as possible the institutional, individual and informal resources available to children and families. The Part H central directory and information resources of maternal and child health agencies are or will be important tools for the discharge planner as well.

Engaging resources beyond the hospital in planning for the child and family well before discharge is a second task, to be combined with ongoing discussion with the family. For example, when an infant is identified early on as potentially eligible for early intervention services, the Part H representative, possibly serving as an interim service coordinator, may attend NICU staff meetings during the baby's hospital stay.

The **discharge planning meeting** should be as inclusive as possible. Hospital medical, nursing, nutrition and social services staff are involved. The financial counselor attends or

sends a report. Representatives from Part H and the Title V agency for Children with Special Health Care Needs (most likely the local health department) attend. The community health nurse and other appropriate local providers should participate, either in person or by telephone. The immediate family may be accompanied, if desired, by a relative, friend or parent support group representative. For a child like Hope, a discharge planning meeting should ensure that:

- the child is enrolled, with parental approval, in a tracking system that will link her to a primary health care provider;
- the child is referred to an outpatient specialty clinic as indicated;
- appropriate community referrals are made (in Hope's case, between the NICU dietitian and the local WIC program, concerning special formula and feeding recommendations for Hope);
- the family has an interim Individualized Family Service Plan, if they choose to pursue Part H services, and the opportunity to have an interim service coordinator;
- the family approves and signs the care plan; and
- the family has a copy of the medical record (in some states, families receive a "health passport," a document that contains a summary of the child's course in the hospital, major medical problems, central directory and individually relevant telephone numbers, and other information).

Immediate follow-up, within 24 hours after discharge, should involve contact between NICU staff or the hospital social worker and the family or community health nurse. The call not only provides an opportunity to address unanticipated problems, but also models an ongoing connection among family, hospital and community resources.

"Bridgeship"

Some Health Focus Meeting participants used the term "bridgeship" to describe a talent for spanning the chasms that may separate staff in a hospital from community-based practitioners, estrange the culture of an institution from the culture of a neighborhood, or divide one professional tradition from another. Everyone could describe the "bridgeship" expert—the individual who has established mutually rewarding relationships with people in all sorts of roles and settings, and who can mobilize them to work cheerfully together on behalf of a child and family. One of the chief challenges involved in implementing Part H may be finding a way to make bridgeship a feature of institutions as well as of individuals, so that

respect, trust and collaboration become part of the culture of care.

Lessons from Infants, Toddlers and Their Families—A Summary

As suggested in the preceding text, the exercise of imagining Adam, Eva, George, and Hope and their families serves as a reminder of the intricate links between health and development in the first three years of life. Widespread discrepancies between best practice and the levels of care actually available to children and families were apparent in the group's discussion, and are troubling. The origins of many health and developmental problems of children remain poorly understood, and good information remains, all too often, poorly disseminated.

The provisions of Part H of the Individuals with Disabilities Education Act (IDEA) give states the opportunity to address these issues through the development of policy and a comprehensive system of services. For example:

- Eligibility criteria can take into account the interaction among multiple risk factors as well as the likely effects of established conditions.
- The ongoing IFSP process should reflect evolving family concerns, priorities, and resources.
- Public awareness provisions, the central directory, certification of personnel, and a comprehensive system for personnel development all speak to the need for accurate information and appropriate training for all who are, or may be, in a position to assist infants and toddlers with disabilities and their families.
- Incentives for collaboration are a response to the dimensions of the challenge.

As was suggested in the introduction to this issue paper, however, these opportunities come at a time when health, education, mental health, social service and other systems are highly stressed—faced with unprecedented demands and jeopardized by a scarcity of resources. Stress extends throughout every level of federal, state and local government.

The exercise of imagining Adam, Eva, George, and Hope revealed the ways in which these systemic stresses might affect individual children and families. The process also reminded Health Focus Meeting participants that it is individual practitioners and policymakers who allocate resources traditionally

or imaginatively, who interpret policy rigidly or flexibly, who guard turf or share responsibility. Consequently, discussion turned to the roles and responsibilities that families, health care professionals, and other early intervention professionals may assume in order to promote the health of infants and toddlers with disabilities.

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Section Three: Roles and Responsibilities

Promoting the health of infants and toddlers with disabilities calls for a blending of service traditions, within partnerships devoted to a common mission. Part H challenges traditional ways in which professionals have worked. The Part H statute and regulations do not generally assign roles and responsibilities to specific professions or categories of individuals. Rather, they recognize that appropriate experience and training may prepare practitioners from a range of disciplines, family members, and community volunteers to assume a variety of roles. For example, the Individualized Family Service Plan, a central element of Part H, provides a vehicle for the roles and responsibilities of the people involved in supporting the health and development of a young child with a disability to be negotiated, and explicitly stated.

Participants in the Health Focus Meeting included parents, representatives of professional disciplines long accustomed to working with infants and toddlers, and members of disciplines that traditionally serve older children or adults. They recognized that since "everyone's responsibility becomes no one's responsibility," it is critical in the implementation of Part H that assignments be clearly understood. There must be recognition that disciplinary competencies are not interchangeable, unless proper training and supervision are provided. Moreover, our society, through its licensing procedures, has delegated certain specific responsibilities to specific professionals, just as its laws have reaffirmed families as the primary, and in most cases ultimate, guardians of their children's well-being and development.

The Physician Education Project on Developmental Disabilities at the University of Wisconsin suggests that professional practice with infants and toddlers with disabilities and their families can comprise four areas of responsibility. (Although these categories were developed with physicians in mind, Health Focus Meeting participants found them applicable to other professions and to parents as well.) These areas of responsibility are:

- direct care;

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- coordination of care;
- informing and counseling; and
- community advocacy.

Different professions will see these four areas as compatible with their traditions or a departure from tradition. Individual practitioners will vary in their skill and interest in the four areas.

Direct care

Direct care of infants and toddlers with disabilities includes the nurturing provided by families as well as experiences in a variety of community settings. Direct care responsibilities connected to the promotion of health within the context of Part H include activities related to health promotion and disease prevention, medical care for acute and chronic illness, and habilitative/rehabilitative care.

Each health and early intervention profession has its own conceptual framework and tools for assessment and evaluation. Assessment approaches, including naturalistic observations, may be blended to provide a comprehensive picture of a child and family's situation that will inform clinical judgment. However, a specific diagnosis that identifies the physiologic basis or etiology of a medical, health or developmental disorder requires adherence to a well-established and specific protocol.

Each health profession has developed recommended behaviors and/or treatment techniques for health promotion and disease prevention, for healing, and for habilitation/rehabilitation. As demonstrated by the experience of home care for children with special health care needs and in transdisciplinary early intervention practice, individuals with differing backgrounds, given appropriate training and supervision, can master many of the skills required by complex circumstances.

Some health-related direct care responsibilities cannot, by law, be shifted from one professional to another. However, regulations governing the boundaries of independent practice are changing. Since levels of personal competency will inevitably differ, it becomes the responsibility of each individual parent or practitioner to acknowledge the limits of his or her expertise.

Shortages of personnel who are adequately trained to work with infants, toddlers and their families exist in virtually all medical, health and early intervention professions. It is the responsibility of health and early intervention professions, and of those responsible for establishing adequate systems of care,

to ensure a supply of personnel qualified to support the health and development of infants and toddlers with disabilities.

Coordination of care

Coordination of the care of infants and toddlers with disabilities should take place within disciplines, among professionals from different disciplines, between families and professionals, between different service delivery systems, and among funding sources. The traditions of some health and early intervention professions have seen service coordination as a core component of practice; others have not. Some individual practitioners may be eager to offer themselves to families as the primary coordinators of care for an infant or toddler with a disability; others may be reluctant. Part H specifically encourages flexibility. The goal is to support family choices and preferences.

It is important to recognize that individual parents and professionals can take meaningful responsibility for coordination without assuming total responsibility. Once again, candid negotiation of roles and explicit assignment of responsibility are important. For example, one primary care physician might offer to take on the specific task of coordinating diagnostic findings from medical colleagues and interpreting these to a multidisciplinary early intervention team. Another primary care physician or nurse specialist might be prepared to coordinate a wide range of medical, health and developmental services for an infant and family.

Some families may be faced with the prospect of multiple "case managers." It is important to recognize the distinction between a financial coordinator, who may help a family deal with systems anxious to contain costs or limit service duplication, and a care coordinator, whose role is to ensure the family's access to service.

Informing and counseling

In working with infants, toddlers and their families, health and other early intervention professionals offer parents both anticipatory guidance and counseling to support informed decisionmaking. The context of Part H, with its emphasis on family-centered care, requires a reconsideration of some traditional approaches to informing and counseling, both in the development of the IFSP and in the provision of services to children and families. For example:

- Some professionals have been accustomed to the role of "expert." The professional provided information, and a

family who did not understand the information given or follow professional recommendations was labelled "non-compliant."

- Other professionals have been trained to listen to underlying themes rather than overt content in families' communications. These professionals may discount families' statements or be reluctant themselves to answer direct questions.

Part H, and family-centered care in general, envision more straightforward communication between parents and professionals as equal partners in a relationship. Just as relationships and development of trust take time, equality in partnerships takes time. Many short, frequent contacts may contribute more to the establishment of trust than one or two lengthy "informing" sessions.

A flow of information is critical in a system of care responsive to infants, toddlers and their families:

- Anticipatory guidance should be seen as a primary means of encouraging positive caregiving.
- Support for informed decisionmaking should include careful attention to the language and circumstances in which information is shared; circumstances that encourage families to raise questions and discuss options, with time for thoughtful decisionmaking by all; and behavior that conveys respect for family choices.

Community advocacy

Thoughtful health and other early intervention professionals have long recognized that systems change may be the most effective route to improvements in the health and developmental status of young children. The need for reallocation of financial and human resources and/or changes in the configuration of human services delivery systems is apparent to many.

Advocacy is a citizen's responsibility. Advocacy may be incorporated as an area of professional responsibility through a variety of activities:

- Family members, practitioners and others may advocate for an individual child and family to make sure that existing health, medical and other services are accessible and responsive to individual needs.
- Advocacy for attention to the population of infants and toddlers, or for attention to young children with disabilities, may be undertaken within associations or groups that are concerned with child and family issues across the lifespan.
- Practitioners and families may join others in advocating for

new ways of conceptualizing and organizing services in executive branches at all levels of government, as well as within agencies providing direct service.

- Experienced professionals have commented that it is often easier to sway a state legislature than a university curriculum committee. This comment speaks to the need for advocacy to focus attention on the medical, health and developmental needs of infants and toddlers with disabilities and their families within training institutions, corporate board rooms, private foundations, the media, and other arenas of authority and influence.

This discussion of roles and responsibilities has focused on **behavior.** Public policy can influence the behavior of individuals by offering incentives and leadership toward certain goals. Elected officials and administrators can invite individuals to engage in the process of policy development, with the aim of creating a common agenda endorsed by the public, private, and voluntary sectors.

Using the four areas of responsibility listed above as a framework, the final section of this issue paper will identify policies and strategies likely to promote the health of infants and toddlers with disabilities within the context of Part H.

Section Four:
Policies to Support People

National policy **exists,** in the form of statutes and regulations designed to achieve comprehensive, family-centered, community-based coordinated care for infants and toddlers with special needs and their families.

National policy is **evolving.** Media attention often is focused on proposals for major new legislation, such as the effort to legislate some form of national health insurance. But new legislation is not the only way to change national policy. Each reauthorization of existing legislation provides an opportunity to correct problems that have been identified during the process of implementation, and to address emerging needs. Reforms can be made in existing programs, as is occurring with Supplemental Security Income (SSI) after judicial review. Funding levels for categorical programs and block grants are renegotiated continually. Administrative reorganizations occur.

Moreover, policymaking is not just a federal activity. Each state uses the variety of resources available in ways that reflect its own resources and priorities. Professional associations, private insurers, educational institutions, child and family advocacy organizations, and other entities shape public policy. As participants in the Health Focus Meeting emphasized repeatedly, national and state policy become a reality for most children and families at the community level, in their daily interaction with practitioners and institutions. At all levels, the translation of policy into changed behavior takes time.

In recent years, many policy analyses and guidelines for implementation have addressed issues related to the health of children with disabilities or special health care needs. In an effort to build upon, rather than duplicate, previous thinking, participants in the Health Focus Meeting sought to identify policies and strategies likely to support practitioners and parents as they assume new roles in the context of Part H. Some suggestions were prompted by discussions of scenarios involving individual children, families, and service providers: What would make it easier to address the medical, health and developmental needs of Adam, Eva, George, and Hope? Other

ideas emerged from more general discussion of roles and responsibilities. The recommendations that follow are linked to the four areas of responsibility described in the previous section: direct care, coordination of care, informing and counseling, and community advocacy.

Policies and strategies to improve direct care

Our country is struggling to resolve many basic issues concerning the delivery of medical, health and developmental services to children and their families. A spectrum of medical and health services, including complex subspecialty and specialty care, somewhat less complex specialty care, and preventive and primary care, is frequently not available at the community level. Health Focus Meeting participants recognized, but could not address in the limited time available, such barriers as inadequate professional reimbursement and other incentives, workloads, and the special demands of rural and inner-city settings.

To create a continuum of care at the community level, strong linkages must be established between large medical centers that provide the most complex care and community health professionals who provide specialty and primary care.

Training, in all of its forms and dimensions, was mentioned most often as a means to raise the level of accepted practice in serving infants and toddlers with disabilities and their families. Particular attention was paid to the issue of integrating medical, health and developmental perspectives in training. Here are some suggestions:

- The state maternal and child health agency, whether or not it is the Part H lead agency, should be involved in planning the Part H Comprehensive System of Personnel Development in each state.
- The federal Office of Special Education Programs should use health consultants in reviewing personnel preparation grant priorities and applications.
- Maternal and Child Health Bureau support for training health professionals to work in the context of Part H, as is occurring in a University of Kentucky-based project involving public health nurses in 14 states, should continue.
- The Office of Special Education Programs should continue to make its Division of Personnel Preparation funds available to train multiple disciplines.
- In their standards and guidelines for practice with infants, toddlers and their families, professional associations should delineate discipline-specific competencies related to promoting the health of infants and toddlers with disabilities.

- On-site technical assistance, inservice training, and continuing education should be made available to private practitioners as well as publicly funded agencies.
- Funding should be made available to allow health care providers to consult with early intervention programs around the health needs of individual children as well as programmatic health and safety issues. Similarly, other early intervention professionals could provide their expertise directly to medical and health care settings. Jointly funded positions or personnel "purchased" by one agency to work in another can institutionalize this ongoing training approach.

The **process** of training may be as important as content in bringing about change:

- Undergraduate education should be seen as an opportunity to recruit potential practitioners in the medical, health, and developmental professions.
- Interdisciplinary training, at the levels of preservice, inservice, and continuing education, should help to create a sense of shared mission with respect to infants, toddlers and their families, while at the same time engendering respect for the complementary contributions of individual disciplines.
- Professional associations, individually and in collaboration, should use training addressed to the immediate perceived needs of practitioners as an opportunity to begin a dialogue concerning broader medical, health, and developmental issues.
- Agencies involved in the implementation of Part H should collaborate on training.
- Leadership training for health and other early intervention professionals who already practice family-centered care can reinforce their commitment and give them the tools to influence and support a growing network of colleagues.
- Parents have a unique impact as trainers of professionals. They are currently engaged in classroom teaching, involved in practicum experiences, and reaching large audiences through conference presentations, publications and videotapes. It is important to continue to recruit and train new parents for this role.

Policies and strategies to improve coordination of care

Exhortations concerning coordination and collaboration need to be backed up by meaningful incentives. Here are some suggestions:

- Reimburse professionals in private practice for attending discharge planning, IFSP development, case management and other meetings related to services for the child.
- Experiment with locating health and other early intervention services and personnel at the same site.
- Use staff of tertiary care medical centers to provide technical assistance and consultation in the organization and upgrading of community services.
- Reward community service agencies for outreach to underserved populations and for providing training to tertiary care centers.
- Always include representation from all agencies involved in services to infants and toddlers, as well as private health and medical care providers, on local Interagency Coordinating Councils.
- Give real responsibility to the Federal Interagency Coordinating Council for Part H, such as reviewing the regulations of federal Part H, Title V, SSI, Medicaid, and related legislation to identify areas of compatibility and conflict.

Policies and strategies to improve information flow and consultation

Incentives are needed to stimulate the flow of information that is essential to a competent system of care. Here are some suggestions:

- Parents need to be given copies of health documents, assured access to medical records, and informed about where records have been sent.
- The Part H central directory of services and the newly mandated Maternal and Child Health/Children with Special Health Care Needs toll-free number in each state should be coordinated, if not combined.
- Physicians and others involved in the caregiving team need an ongoing source of medical consultation.
- Part H public awareness initiatives should target primary referral sources.
- The child find, identification, and referral process, within and among disciplines, should be used as an opportunity for individuals and institutions to inform and counsel each other. University Affiliated Programs might take the lead in offering training and technical assistance to referring sources.
- Community planners need clear interpretations of all applicable statutes and regulations.

- The Office of Special Education Programs should use health and social service consultation in reviewing state applications for Years IV and V of Part H funding.
- Part H technical assistance efforts should include opportunities for state and community-level discussion of health promotion within Part H. This paper could be used as a starting point for discussion of those health integration issues most relevant to the state or community's own circumstances.

Policies and strategies to improve advocacy and planning

Individuals and organizations that share a commitment to improving the chances for optimal health and development of infants and toddlers with disabilities and their families will not necessarily agree on priorities, strategies or tactics. If important issues that concern the content and organization of care for infants, toddlers and their families are to be resolved, it is crucial that everyone involved with this population be engaged in the process of policy development. Here are some suggestions:

- The participation of families must be supported at all stages of policy and program development and implementation.
- Community planning processes around services for infants and toddlers with disabilities and special health care needs should be encouraged, as likely to lead to community "ownership" of responsibility for these children and their families.
- At every level of planning, there should be representation from public, private, and voluntary institutions and associations.
- The Federal Interagency Coordinating Council members should become advisors and problem solvers for Part H, modeling collaboration and the integration of medical, health and developmental perspectives.

Essential to the development of a broadly supported common agenda for infants, toddlers and their families is the recognition that meaningful policy cannot be dictated—from one level of government to another, from the public to the private sector (or vice versa), or from a single professional tradition to others. Part H offers opportunities and challenges to every individual, every institution providing care and training, and every public agency currently or potentially involved with this population. Coming to the table, beginning and continuing a conversation are the first steps toward promoting the health of infants and toddlers with disabilities through Part H.

Appendix A

Selected NEC*TAS Publications

*Note: These publications have previously been distributed to Part H Infant and Toddler Program Coordinators, Part B, Section 619 Preschool Special Education Coordinators, and Interagency Coordinating Council Chairpersons in all states. For additional information on other relevant products, contact the NEC*TAS Coordinating Office at (919) 962-2001.*

Burnim, I., et al. (1990). *Strengthening the role of families in states' early intervention systems.* MHLP/NEC*TAS/DEC.

Available from:
Division of Early Childhood
Council for Exceptional children
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660

Edmunds, P. et al. (1990). *Demographics and cultural diversity in the 1990s: Implications for services to young children with special needs.* NEC*TAS/PACER.

Available from:
PACER, Center Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417
(612) 827-2966

Information packet on the financing of early intervention and preschool services. (1990). NEC*TAS.

For availability information, please contact:
NEC*TAS Coordinating Office—Publications Section
CB# 8040, 500 NCNB Plaza
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-8040
(919) 962-2001

Johnson, B., et al. (1991). *Guidelines and recommended practices for the individualized family service plan* (2nd ed.). NEC*TAS/ACCH.

Available from:
Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

Lindgren, J. (1989). *Bibliography of selected resources on cultural diversity.* NEC*TAS/PACER.

Available from:
PACER Center, Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417
(612) 827-2966

Meisels, S., & Provence, S. (1989). *Screening and assessment: Guidelines for identifying young disabled and developmentally vulnerable children and their families.* NEC*TAS/NCCIP.

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National Center for Clinical Infant Programs (NCCIP)
2000 14th Street, North, Suite 380
Arlington, VA 22201-2500
(703) 528-4300

Williams, S., & Kates, D. (1990). *NEC*TAS financing workbook: Interagency process for planning and implementing a financing system for early intervention and preschool services.* NEC*TAS.

For availability information, please contact:
NEC*TAS Coordinating Office—Publications Section
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